



Green Mountain Self-Advocates

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My name is Max Barrows, nick name is Max. I am the new outreach worker for the Green Mountain Self-Advocates (G.M.S.A). I am on a legislative committee figuring out how to make services better for people with autism.

One of the reasons the committee picked me to be a part of this is because I have Autism myself and growing up with the disability has been a rollercoaster ride with lots of ups, downs and spirals. There are a lot of people on this committee that are concerned about the needs of people with Autism, but very few of them actually have Autism! I feel the voices of people with Autism are missing, that is why I invited teenagers and adults who have an autism spectrum disorder (autism, Asperger's or pervasive developmental disorder) to tell me about their experience living with autism.

Below are the questions and the answers people gave me.

Autism shows itself in different ways. (It is not just autism but disabilities of all kinds can be a challenge.)

It is very important to recognize that there are so many different types – therefore people need different kinds of supports.

1. What would be a way to recognize so many different types of autism?

The only way to recognize autism is to do an evaluation that requires taking a developmental history, doing psychological testing. Recognizing certain

characteristics – like their social interactions. It is quite involved – usually takes several hours.

Track them. Have periodical check ups on how they do and how they react to certain stimulus. I didn't recognize I had it until later. I found out I had it at age 13. I am sensitive to bright lights, loud noises. Test to see if they have sensitivities to certain stimuli.

I can tell if someone has a job coach or a paraeducator working one on one with a child at school.

They will not necessarily look into your eyes or have interest in your conversation. Some may be super smart and can drive like my boyfriend who I have been with for a month and a half.

2. How have people supported you to speak up for yourself? What do people do that is most helpful for speaking up?

My mother is very involved with autism groups. She is very supportive of me. But specific to help with speaking up for myself – basically I have had to learn on my own. Through conversations, I had to make up for my difficulties. Maybe some are more successful...I am sure there are many people with autism who are not as successful speaking up for themselves.

In the past, having my father with me when I go to my IEP meetings helped me speak up and learning self-advocacy skills.

Sometimes it is very hard for people with autism to speak up, but you need to speak up so you can get the kinds of services you need. For people like me, it has been hard for me to speak up.

I have been very good at public speaking. I am provided support to keep going. But when I try to set boundaries, people don't always listen. It can be hard to get people to listen.

Some people are tense about speaking up, having to face things. There have been quite a few people who helped me speak up for myself. Tracy helped me and also my guardian.

S.G. helps me speak up if I need help with a problem on the job. S.G. will help with team work and we have meetings we process all the problems I have.

I speak up for myself most of the time. Rarely do I need to be asked to speak up. But my boyfriend always needs help when it comes to speaking up he feels embarrassed to tell it or say it. He can't speak up he laughs and looks at me. Maybe to help he could take a social thinking class.

3. What were your experiences growing up as a child with autism in this process?

Well I certainly had a lot of problems in school. In elementary school I had friends but after that I didn't interact with people. I had problems socializing. Being lonely has been a source of terrible anxiety for me. That continued until rather recently. I could use more social interactions. They are quite limited. I have made spiritual progress and it is very important to me. I am Catholic and I am on medication.

Social interaction is critical. People with autism they desperately need help with social interaction. The Support groups are for 18 to 30 year olds. There are none for 42 olds. I badly need a support group to go to.

Given that I have a skin disorder I have been teased a lot, picked on by other kids. I liked the mainstream classes, Sometimes I think I wasn't put in

mainstream classes enough. Sometimes people with autism stay alone. They don't interact like other people do. They don't go to the movies. They spend a lot of time alone in their room. I never had friends in my home town.

Growing up as a person with autism can make you feel so different from everybody else. One of the challenges for me was being lonely and feeling like I was one of the few who was so different from everybody else. Because of that a lot of people didn't understand me throughout my childhood. I had no connection.

I felt different than others and feel isolated.

Schools try to make kids blend in but people don't make room for me to fit in. I am not included. I am ignored.

I knew that I had a difference, but I didn't know what it was. My parents told me at age 16. Then I studied my disability and found out why I was like I was.

The challenge I faced was being an outcast because I didn't know how to interact. I was an outcast at school and in family. I was interested in history, my family was not. They didn't read. They beat the crap out of me. I didn't fight back. I was harassed and quit elementary school. Then I went right to high school. I felt really awkward. It was hard going right to high school and not to middle school. It was hard to adjust. Kids laughed at me in sex ed for asking obvious questions.

I moved around a lot. I moved to a lot of different homes and schools, lots of different high schools. Some years were easier than others. It was hard to adjust to the changes. Akuna Matat: I put my past behind me.

I was bullied. I didn't get any social skills training.

I thought school was God. I did everything I was told. Then I realized that school was not God and I ended up in a psychiatric hospital.

Well until I was 4 years old I did not talk. I had a rough life when I was young. Since I had seizures for 9 years like every hour. I has one my Mom could not find the right prescription of pills for me. But otherwise I had an okay life. I just got a boyfriend who is very much like me and has autism.

I had different vocational job experience had life skill experience learned how to have accounts and how to type. I do have some experiences I need to work on.

4. Is there any way people with autism can be more accepted? More noticed? More connected to the world? How about starting in their childhood?

Early intervention is important – it prevents complications. It requires evaluations to be done – as early as possible. People need to be understanding of people with autism. Later on what is critical is to be understood and accepted and for others to reach out to people with autism because they need support.

People, employers need to be more understanding – more willing to hire people with autism. It is very hard to find employment. The interviewing process is very difficult. More employers need to be more understanding and accepting. Studies show employers are more willing to hire people with more obvious disabilities – like someone using a wheel chair but they are not as willing to hire people with more subtle disabilities like autism or mental health disabilities.

More peer groups – more support groups – more early diagnosis

Charles Darwin and Mozart had autism. Mozart was accepted because he had a gift that he could contribute. I did a lot of music writing myself. I asked for advice from my aunt and grandmother to help form myself and on how I think. I get frustrated easily when I don't understand. I might get rage from that. I might say or do hurtful things. I seek advice to not do that. It helps if people make things clear. I focus on people's mouth because it is hard to make eye contact. It makes it hard to understand what person is saying. I miss a person's body posture and facial expressions.

I am working on active listening and getting clear instructions.

Well I think the way to get autistic kids more accepted and connected to the world is to get them social thinking therapy at an early age.

Good helpers and mentors who teach one another helped me feel more accepted and noticed even more connected to the world. That's how to be more accepted

5. What can people do to help build confidence in you? And make you feel confident?

If I could find something more worthwhile to do with my time or if I could find a job, that would help me to be more confident. Also help to have more social interactions.

Offer positive feedback which can be very motivating. Provide a comfortable environment, an environment where you can feel accepted – it is like what Barbara's house is.

I didn't have much transition time between school and real world. I got myself a job coach. I took an active role in finding a job. I am learning to have a good feeling about earning money. I am learning how to manage money, how to prioritize what to buy. I struggling with budgeting, I didn't

have much as a child. I can accomplish things that my family can't do. I am able to contribute to my grandmother's headstone, I felt really good about it. I felt I made a contribution and it made me feel more confident.

Transition to adulthood is easy for some but not so easy for others. For some it leads to a path towards independence, for others it leads to having roommates.

Wanting everything to stay the same as it is now, but knowing that I need to let things change and move forward. It can be a battle and can lead to depression. People should push, but not too hard.

I feel confident when I learn something. Education helps me feel confident. I know how to do lots of physical things and how to mentally behave myself.

6. In what ways can people with autism be prepared for the real world – so you don't feel discombobulated?

They need a lot of help. There is no way around that. There is not a lot they can do on their own. They need help with socializing and getting a job. Services they need do not exist – unless their IQ is under 70 – they need to be willing to fund these services for all people with autism.

Every high school should have an apartment or community living program. More job groups like *Hire Up* that discuss how to get a job, how to make a good impression.

I want the security of being in programs that help support me, helping to make things feel stable. I need a secure home away from home. I advocated to be my own guardian. I am trying to get section 8. Staff prepared me not to drink because that would interact with his meds. They told him that mixing alcohol with meds could kill me. This is institutional

thinking. There were many talks to help me vent my feelings. I need a secure place to feel grounded.

Both worlds are extremely different (school and the real world). School is academics. The real world, we are facing it too soon, if you had bad experiences in school, you might not face the real world with as much confidence. The real world is jobs. Jobs require a HS diploma. For those who don't have that, they have a really hard time finding a job.

Try their hardest to be around a big crowd of people and be social and try to control their anger and frustration.

I had to learn how to be flexible, stay in social boundaries by trying to control infatuation, obsessions and how to get a job and use money wisely so I could purchase.

7. Feeling good about yourself is an important thing to have when you are no longer a child and you enter adulthood What should people do to help you and others feel good about yourself while in that process?

Help with getting employment. Help with socialization.

It is important to be around support people, getting voc rehab support, getting residential support. I like having people to show me the ropes of living independently, how to make connections and network. Providing positive feedback and providing accommodations to meet various needs. Being given more independence.

Hearing good compliments. Taking small steps into the adult world. Slowly going to meetings at first, then going to them for longer and longer. Think positive thoughts and do self-affirmations to help you feel better on bad days. I need lots of people to support me. We need to better educate the

community. Putting up signs indicating that a child has a disability can make people avoid them.

ASD can be a good thing or a bad thing. Labeling can be bad, it makes people have assumptions. We don't want to be thought of as *weirdos*. We are very intelligent.

Treat everyone equally. I do feel I am treated equally.

I wish people would be inquisitive about people's challenges instead of the person with disability having to explain it.

Make compliments, praise me for stuff that I never would have done without it.

Support people help me do my work efficiently and make sure I follow guidelines. Sometimes they'll do teamwork with a challenging job. When we have meetings, that helps.

8. While learning in school, do you think people with autism should be in a class all by themselves to learn or should they be with other people without disabilities?

Well – that would depend. Some people with autism might be able to be in regular classroom on their own. Some may require additional help.

I think that they should be in the mainstream with classroom accommodations.

Everyone should be intermingled in classroom to learn better social skills. If separated, will get isolated and picked on and cause problems.

Should be in the class with other individuals because if in class by oneself, that child would eventually get the need for other classmates to be around.

At first when I was taking special ed, the other kids with disabilities didn't understand me. But in regular ed, the other kids didn't understand me either. I am amazed that kids with more visible disabilities thought I didn't have many challenges. Eventually they learned about each other's challenges and made friends. We had a lot in common. We shared struggles. It is a learning process for other kids to understand disabilities. But people can learn from each other. It is okay to have a quiet space available when needed, but do not force it on people.

Try to encourage schools to offer more courses to people with disabilities to learn better.

In integrated setting, people can learn that they are just people, not "disabled" people. Use people first language. That is putting the person first who happens to have a disability.

I hate being in high school because the work is too hard.

Some autistic children should take independent courses by themselves with their paraeducators. And in regular classes as long as it's not too hard

*9. What has been most helpful for you when it comes to support at home?
At school? In adulthood?*

My mother is as supportive as she can be. I haven't received other support except when I was in a special class in 5th and 6th grade – but not specifically for autism – I was diagnosed with learning disabilities. Basically I just struggle on my own.

Having my father always be there for me when I went through the process of getting developmental services. Getting involved with self-advocacy because it teaches us how to advocate for ourselves so we can go for our goals.

Trail rides on a horse with my boyfriend. Weekly riding lessons and barrel racing lessons. I always get to ride a really big horse that's an appaloosa as well as driving four wheeler with my boyfriend going on one in front of me.

My family has been very supportive and patient especially with my rages. My teachers at school cared about me and were patient with my rages. S. G. has supported me well with my job and helped me take breaths.

10. What has not been helpful or has not worked when it comes to support at home? At school? In adulthood?

I am among the lucky ones because I can figure out what to do.

One thing that has not been helpful was the approach by my mental health counselors. In addition to my autism I have depression and Seasonal Affect Disorder. I have been hospitalized. Some of the hospital doctors did not spend enough time with me. They just see me for a few minutes, come up with a quick diagnosis and write a prescription and tell me to stop drinking and go to A.A. That was not helpful. They ignored the pain I had and the struggle I had and that was most unhelpful. Of course they were totally ignoring my autism. Now that I have my diagnosis, they are doing a better job. Help with social interactions is critical. Help with getting into employment – but appropriate jobs to their intellectual capabilities. They should not have to settle for washing dishes not appropriate for someone who is very intelligent.

There have been problems with heavy drinking and use of marijuana. A standard approach to treat substance abuse does not work. Only help with problems socializing and getting a job. They are self medicating they need

help with their problems. Unless you remove the cause they will go back to drinking and drugging.

The process that I went through to get developmental services was not helpful. At first they said I got services, then they said no, then they said yes. It made me feel depressed and I hid in my room crying. When they said no more emergency respite money I had a break down in the agency office. The long waiting process with no definite answers took a huge toll on my mental health. (Ex. Living on the edge/anxiety with no definite date on when I would move out of Randolph. And having to get my parents to kick me out in order to get funding.)

My Mom driving a friend's dusty, dirty, icky truck instead of buying a car for 5 months. Is when my boyfriend signs off the internet when we're I-Ming and he does not say good bye.

When my family, teachers and all colleagues tell me I've done something wrong and they yell at me for doing it. I don't like it to be wrong. I try to do my best at things.